Innovations
IN CONTINUING CARE
VOLUME 2, NUMBER 1, WINTER/SPRING 97

Demonstration Project's approach to evaluation

An evaluation is part of the requirement of the two year Demonstration Project[1] funded by the New Horizons Program of Health Canada. The definition of evaluation being used in this project is "the systematic collection of information about what a program is doing and affecting in order to make decisions about the program", explains Dr. Leslie Gardner, the evaluator for the project. "This project evaluation is meant to provide an overall, global picture of the implementation of the innovative programs, using a descriptive and developmental approach. It is different from and complementary to the EPICC Project, which is conducting in-depth, detailed research on clients and services in three of the six models in the Demonstration Project."

It is important to the participants in the Demonstration Project that the evaluation continue the Project's commitment to a partnership approach. This means collaboration among representatives of consumer groups, providers of continuing care services, and funders during all phases, from evaluation to reporting of results. This approach provides incentives to the continuing care system for implementing the new vision, and encourages innovative programs that contribute to seniors' independence and quality of life.

The design for the organization and management of the Demonstration Project includes the New Horizons Directors, the Project Consultation Group and the Demonstration Project Team. The Directors are a group of mostly seniors, who have many years of experience planning, providing, and advocating for services for seniors. Because they are responsible for the overall direction and management of the New Horizons Project and its funds, they are the major clients of the evaluation. The Demonstration Project Consultation Group is comprised of representatives from the twelve demonstration project sites. This group offers peer support, information sharing, and consultation with each other about project implementation. Other clients of the evaluation, include Health Canada (which funds the project) and the sponsoring partners of the Demonstration Project.

The process for developing the project evaluation plan involved listening to people describe what they wanted to see from a descriptive evaluation. A list of evaluation objectives, principles, evaluation questions, and information sources was then drafted by Dr. Leslie Gardner. The evaluation plan was then reviewed by clients of the evaluation, particularly, each of the representatives from the Demonstration Project sites, and the New Horizon's Directors.

The objectives of the evaluation are:

- to assess the degree to which the design of the individual programs in the Demonstration Project were implemented as intended,
- to assess the degree to which the goals of the Demonstration Project and its stated expectations were met, and
- to make observations and offer comments about the role of a demonstration project as a mechanism for practicing change within a system.

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[1] A project funded by Health Canada's New Horizons Program

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Demonstration Project's approach to evaluation

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Guiding Principles

The evaluation is being conducted according to the following principles:

Descriptive – it involves documenting and assessing things as they are rather than conducting an experiment.

Developmental – the evaluation describes the stages of the Demonstration Project and the implementation of the 12 innovative programs over time.

Participatory – the evaluation uses input from its stakeholders, particularly the New Horizons Directors, and Consultation Group Members, throughout the process.

Cost-effective – the evaluation uses information that is already available, uses data collection methods that are simple and inexpensive, and provides analyses that are easy to understand.

The new models are intended to serve as alternatives and enhancements to the traditional continuing care system.

One example of this is the Consultation Group's collaborative design of the Client Information Form. After sessions of information sharing about implementing new ways of delivering continuing care services, the members of the group decided on a list of client variables for each of the programs to collect and use for monitoring and evaluation. This information is being used in the evaluation to determine the nature of the target group that each of the programs are serving, and how this has changed, if at all, over time. The information from the Client Information forms will be entered into a computerized database, which will be used to examine relationships among client characteristics. A list of some of the variables from the Client Information Form appears in Figure 1.

The Demonstration Project is intended to stimulate the creation of new models, such as these 12 programs, to serve as alternatives and enhancements to the traditional continuing care system. The evaluation intended to make comparisons among the descriptive characteristics of the clients in these projects with available information about residents of continuing care facilities and clients of community long term care in Alberta.

One of the interests of the Demonstration Project was to pilot-test outcome measures. Two of the utilization variables in the Client Information Form, admission to acute care hospital and admission to continuing care centre, will be used as system level outcome measures to identify system level patterns of health care utilization.

The Consultation Group has agreed to collect data on clients from July 1, 1996 to June 30, 1997. Program documentation review, and interviews with sponsors, site participants, and other

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Figure 1

New Models in Continuing Care Demonstration Project Client Information Form: Data Elements

Admission	Quarterly	Discharge
• Gender • Date of birth • Marital status • Admission date • Type of residence at time of admission • Diagnosis • Reason for referral • List of medications taken in the last month	• Number of visits to an emergency department during the last quarter • Number of admissions to acute care during the last quarter • Number of admissions to Continuing Care during the last quarter • Total number of days in Continuing Care during the last quarter	• Reasons for Continuing Care Centre stays during the last quarter • Date of discharge/death • Reason for discharge • Type of residence after discharge

These data elements are collected on admission, on a quarterly basis, and at discharge.

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Weather permitting, the facility offers easy access to the outside where residents can wander safely through the grounds.

A sense of community and oneness is felt by those of similar heritage and language. The feeling of belonging in a family, which is part of the intent of the Native Heritage Enrichment program, can relieve a great deal of anxiety and confusion. This benefits all of the residents of the centre.

Ma Ma We Atoskitan — "Let's Work Together"

For the program to be successful, it was recognized that consultation, and participation with the Aboriginal people in the region had to be meaningful. An Aboriginal Health Services Liaison is part of the staff of J. B. Wood Extended Care. A significant part of his role is the social time that is spent with residents, and their families. In June, 1996, a S.T.E.P. student was also hired for the purpose of Aboriginal community bridging, to enhance communications with the local native communities. Together, the Liaison staff have visited the reserves, and settlements in the Keeweetinok Lakes Region to interview elders in order to understand the elders' perception of the Native Heritage Enrichment Program operated at J.B. Wood Extended Care. They also work with Recreation Services in the facility in assessing cultural preferences to help enhance understanding between the cultures.

To date, they have been granted permission to go into four of the 12 native communities. In these four communities, they were welcomed into the homes of elders and senior citizens. Cultural beliefs,
traditions, native Aboriginal heritage, and personal histories are discussed. Some of the questions that the Liaison staff ask potential participants of the program, relate to the following issues:

- health condition of the individual,
- preferred health treatment,
- care by a medical physician,
- care by a Native Spiritual Healer,
- type of medication taken/preferred,
- medical and herbal remedies when medication is required,
- daily nutritional intake,
- daily physical activities,
- mental and emotional needs, and
- healing knowledge of the local care facilities.

The Aboriginal Health Services Liaison staff have been instrumental in providing educational sessions for staff of the High Prairie Health Complex and J. B. Wood Extended Care regarding Aboriginal culture, heritage, and lifestyle.
An Aboriginal Elder gave a one-day educational presentation as well.

Aboriginal families have been involved in consultations with the Aboriginal Health Services Liaison staff, and have invited them to local communities to discuss issues such as cultural beliefs, traditions, and native heritage.

Native Heritage Enrichment

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Local Community Care Services provide health care support in home settings for Aboriginal clients before they need to move to a facility. This partnership with Community Care permits early detection and management of many health problems. The Friendship Centre is another community-based service that provides support services to Aboriginal people. These centres make referrals to other local health agencies.

Acceptance of the Program

The Native Heritage Enrichment Program is now accepted and approved of by many of the Aboriginal communities in the region. Evidence of this acceptance includes: the willingness of physicians to allow herbal remedies, and tonics to be independently taken by Aboriginal clients; verbal communication from the Aboriginal communities; and, the fact that family members are now aware enough of the program that they will request alternatives to "hospital system" medications.

Information about the Native Heritage Enrichment program including factors that are critical in making the program work, and indicators of success, can be obtained by contacting:
Ruth Hampton, Coordinator,
Regional Long Term Care,
J. B. Wood Extended Care,
Bag 1,
High Prairie, Alberta,
T0G 1E0.
Phone: (403) 523-3341;
Fax: (403) 523-3888.

1909–1996 MARY DAVIS

Mary was a fine example of someone who cared passionately about the situation of seniors and was vocal in her passion.

Mary Morrison Davis was a major figure in the development of services for older adults in Alberta. In her work as the Chief Social Worker in the Mewburn Wing of the University of Alberta Hospital, with Veterans Affairs Canada, and in her volunteer work, she was a strong advocate for improved services for older adults. She chaired the 1967 Alberta Conference on Aging, and the Edmonton Social Planning Committee which brought about the establishment of the Society for the Retired and Semi-Retired in Edmonton in 1970. She later served as President of the Society. She was appointed to the Seniors Advisory Council for Alberta when it was established in 1976, and was the first Alberta representative on the National Advisory Council on Aging. Most recently, Mary was one of our New Horizons Directors, overseeing the New Models in Continuing Care Demonstration Project.

Personal Tributes:

In memory of a mentor.

Mary Davis died in December 1996. She had a long career of service to seniors and was recently awarded the Order of Canada in recognition of her public service. To me, Mary was a mentor, a model, and a friend. From the time of my arrival in Alberta in the late 1970's, Mary introduced me to the people who were involved in gerontology, talked to me about what were the important issues and

EPICC: Choice, Independence and Authenticity

One of the themes in the EPICC Project is the quality of life of seniors in continuing care. Quality of life has been defined by some Canadian researchers as "the degree to which a person enjoys the important possibilities of his/her life."[1] The vision for continuing care in Alberta emphasizes quality of life and personal independence. "Like people of all ages, seniors in continuing care want a home, they want to do things they like, and they want to enjoy life and have friends," says Leslie Gardner, team leader for EPICC in this area. "Our challenge in EPICC is to gain a better understanding of the elements of quality of life that are especially relevant to residents in continuing care settings."

"Like people of all ages, seniors in continuing care want a home, they want to do things they like, and they want to enjoy life and have friends."

The EPICC work group that has developed the quality of life theme, calls itself CIA. This acronym represents the three elements of quality of life that are seen as fundamental in the lives of seniors in continuing care: choice, independence and authenticity.

Choice

Providing choices is a stated objective of each of the new models of continuing care. In EPICC, we are looking at two types of choices: choices among different types of continuing care programs, and choices in daily living within the chosen program.

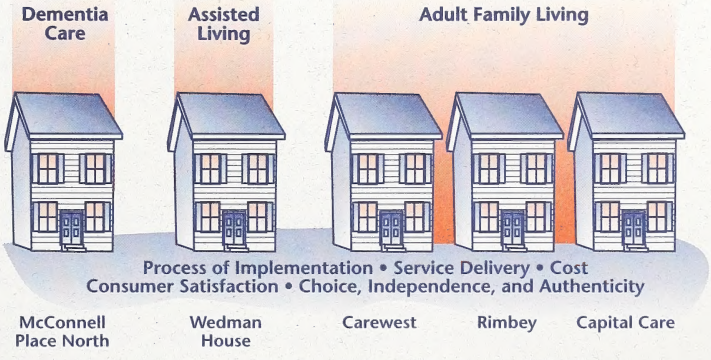
Programs participating in EPICC were developed to increase the range of options in continuing care programs. For example, the adult family living program in Rimbey is a response to consumer requests for more residential continuing care options in their rural setting. McConnell Place North was developed to provide a home-like living experience for people with Alzheimer disease or related dementia who do not require significant amounts of nursing care. Yet choices developed may not be experienced as choices by consumers. Information about available options and access to the option will influence whether seniors and their families believe that new models increase their range of choices.

Choices within programs relate to options concerning what activities are done, and when they are done. One of the basic tenets of Wedman House assisted living program is that residents have the right to personal choice in daily activities, bounded by social norms and safety requirements.

Independence

Traditionally we have seen independence as people's ability to do daily living activities without the assistance of others. However, we believe that independence is not determined by whether or not a person can do tasks by herself or himself, but by whether the person has some control over which tasks are done, when they are done, and who does them. Findings from a recently completed project to define elder care, support this view of independence. Norah Keating found that seniors who felt that they had such control believed that they were independent regardless of their physical abilities.[2] In keeping with the latter definition, we are looking at ways that the physical and social setting in which people live enhance their sense of control, and therefore their independence.

The EPICC Evaluation



* A project funded by Health Canada's Seniors Independence Research Program

[1] Raphael, D., Brown, I., Renwick, R., & Rootman, I. (1994) Quality of life theory and assessment: What are the implications for health promotions? Toronto, ON: Centre for Health and Promotion and ParticipACTION.

[2] Keating, N., Fast, J., Oakes, O. & Harlton, S. (1996). Defining Eldercare: Components and perspectives. Final report to NHRDP.

EPICC: Choice, Independence and Authenticity

Authenticity

Authenticity refers to respecting people's uniqueness, and their right to continue living out their own life story in spite of illness, limitation or disability. It gives meaning to choices when decisions express who each person is, and wants to be. The physical and social settings of residential continuing care may enhance or impede the expression of who an individual really is. The philosophy that guides each model of service that EPICC is studying is explicitly client-centred. The EPICC approach to authenticity is to look for instances in day-to-day life where residents, who have the physical and cognitive abilities to live out their values and preferences, are encouraged to do so. There is also a special place for authenticity in promoting quality of life for residents who have cognitive disabilities. This requires understanding how the personal history, and experiences of each resident's lifetime reveal what choices would be important now, and consistent with personal values and preferences.

"The residents' lived experiences are a fundamental component of their quality of life, and will be extremely important in describing the innovation in the new models."

Evaluating quality of life

Our conceptual understanding of quality of life was developed by reading the literature, formulating a model, and confirming the model with 'real-life' examples. We have had valuable contributions from a work group[3] comprised of site representatives, consumer representatives from the New Horizon Directors, government representatives, researchers and graduate students.

We are using the following methods to describe the concepts of choice, independence, and authenticity across the three models of care participating in EPICC (see figure on page 1):

- Residents are invited to participate in face-to-face interviews. During these interviews, qualitative data are gathered on residents' perceptions of the physical and social setting in which they live, their ability to exercise personal choices that matter, and their links with their community (including cultural or spiritual communities). Quantitative information is gathered on measures of residents' abilities and attitudes.
- Direct service providers from each program are invited to participate in focus groups to discuss how they see choices, independence, and authenticity in their program.
- Family members from each program are invited to participate in focus groups to discuss their views on the availability of choices within the continuing care system, and choices within the program in which their relative resides.
- Selected residents will be invited to participate in interviews to talk about their lived experiences in the program.
- Information on residents who left or were discharged will be obtained from program records where available, to capture the variability in resident experiences.

Cheryl Nekolaichuk, EPICC research associate comments, "the work group's challenges and frustrations of dealing with intangible concepts like choice, independence, and authenticity were counterbalanced by the commitment, energy and lightheartedness of group members. It was the dedication of group members that carried the work group and enabled it to complete its task."[3] Rosalie Kane, a gerontologist, and Kathryn Allen, a qualitative methodologist, consulted with us on the refinement of our methods.

We are currently interviewing residents, and conducting focus groups with staff and family members. EPICC research associate Annita Damsma comments, "the exciting part of this theme is talking to people about what it's really like to be part of these new continuing care programs. The residents' lived experiences are a fundamental component of their quality of life, and will be extremely important in describing what is innovative about the new models."

If you have questions, please contact the project at **403-492-2865**, fax **403-492-3012**, or e-mail at **jacquie.eales@ualberta.ca.** Or you may write to: **The EPICC Project, Room 3-43, Assiniboia Hall, University of Alberta, Edmonton, AB, T6G 2E7.**

[3] Members of the work group are: Leslie Gardner, Jacquie Eales, Liz Broad, Wanda Cree, Norah Keating, Cheryl Knight, Carole Marshall, Cheryl Nekolaichuk, Mary Norman, Barbara Ryan, and Gayle Sawatsky.

Native Heritage Enrichment

J.B. Wood Extended Care in High Prairie (Keeweetinok Lakes Regional Health Authority) has developed an innovative program to recognize the unique needs of the Metis and First Nations populations. Aboriginal people utilize approximately fifty percent of the beds in the facility. This project recognizes that appropriate care for older adults in continuing care facilities must be individualized, and take into account clients' heritage, sociological background in comforting physical surroundings.

Cultural Values Respected

A holistic approach to health care is being used in this program, including traditional native medicines such as herbal remedies, teas, ointments and homeopathic remedies. Choice of treatment, including traditional native medicine, is offered to Aboriginal residents. This holistic approach has involved significant education of facility staff. Now, quite often the Medicine Man or Woman, and the physician collaborate in the treatment of an Aboriginal resident. Particularly with palliative care, this gives the resident a great deal of "soul" peace. Sweetgrass is burned as a traditional ceremony, and prayers are held every morning at the centre. Sweetgrass is grass that is picked from local fields and braided. The smoke from the contained flame is considered a purifier.

A large part of most people's enjoyment in life centres around food. The Aboriginal population is no exception. They have hunted and fished for most of their lives. In their elder years they are often placed in situations where their traditional meals of venison, moose, rabbit, fish soup, and bannock are not available. Familiar tastes may add a sense of security to their environment. Elements of the traditional native cuisine have been incorporated into this Native Heritage Enrichment program. At the annual celebration of Pow-Wow Days, families come together with their elders to celebrate their culture, and make traditional meals.

Aboriginal cultural decor, including dream catchers, mocassins (which have been pinned to the walls), and native art, has been incorporated into J. B. Wood Extended Care. The love of the outdoors is inherent in the lifestyle of most of these Aboriginal residents.

Demonstration Project's approach to evaluation

continued from previous panel

stakeholders will take place in the spring/summer of 1997.

The first draft of the Demonstration Project evaluation report will be completed in late 1997.

This issue of Innovations in Continuing Care will feature the Native Heritage Enrichment Project in J. B. Wood Extended Care in the Keeweetinok Lakes Regional Health Authority. The next issue of Innovations will feature the four Transitional Care Projects.

The second issue of Innovations in Continuing Care, Volume 1, Number 2 (Winter, 1995/96), provided a profile of one of our distinguished new Horizons Directors – Mary Davis. On December 30, 1996 Mary passed away. This issue of Innovations features a brief dedication to Mary, as our tribute to the significant contributions that she made to building a better community.

"Volunteering and getting involved just seems to be a natural thing for me to do" Mary Davis said recently. "I don't do it for the recognition, but simply to give to the community, and help build a better community."

encouraged me in the development of my career on aging.

Mary was a fine example of someone who cared passionately about the situation of seniors and was vocal in her passion. She was a member of the New Horizons Directors group that provided some of the most important consultation to the EPICC project. Mary understood the art of lobbying and persevered in her efforts despite great physical challenges in recent years. I will miss her.

Norah Keating
Principal Investigator – EPICC Project Department of Human Ecology, University of Alberta

I first met Mary Davis when I went to work at the Society for the Retired and Semi-Retired. My background was in Social Work with families and children. My information about working with seniors was almost non-existent. Mary became my resource, providing knowledge of the field of gerontology, and consultation about planning services and activities at a senior centre. She supported me when I needed it. She continued to share her interests and concerns with me over a period of more than twenty years. She was an invaluable colleague, and a close personal friend. I shall not forget her.

Wanda Cree
New Horizons Director

Mary Davis and I first met at meetings of the Alberta Association of Social Workers, of which she was an active member. We became colleagues, and friends after I started working at the Society for the Retired and Semi-Retired in Edmonton. I can truthfully say that Mary served as a mentor for me, teaching me and others much about aging, and seniors' issues. She has provided advice and support throughout my years of work with the Society, and later the provincial government. Many of my ideas about aging were shaped by Mary, not only through her teaching but also through her example. Mary was a close personal friend, always there to listen. I and my family, and many others, will miss her support and guidance.

Mary Engelmann
New Horizons Director

Innovations
IN CONTINUING CARE

Innovations in Continuing Care is published four times a year. Submissions, questions, and letters are welcome and should be sent to Project Co-ordinator Bruce Finlayson, c/o New Models in Continuing Care Demonstration Project, 8th Floor, Box 2222, 10025 Jasper Avenue, Edmonton, Alberta, T5J 2P4.

Phone: 403-427-7128 • Fax: 403-427-0767 or e-mail at finlab@mail.health.gov.ab.ca.

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